

Pay More Attention

Ensuring equal access to high quality hospital care and services for children and young people with and without learning disabilities: Phase 1

We are a team of researchers from the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at Great Ormond Street Hospital. We are conducting a national study to compare how hospital care and services are provided to, and experienced by, two groups of children and young people with long-term health conditions - those with learning disabilities and those without learning disabilities.

Definitions

Long term conditions are health conditions that last a year or longer, impact on a person's life, and may require on-going care and support e.g. epilepsy, Cerebral Palsy or diabetes

Learning disabilities mean a person has a reduced intellectual ability and difficulty with everyday activities, which affects them for their whole life.

We are inviting all staff from over 20 hospitals in England who come into contact with children and young people (CYP) aged between 5 and 15 years old, with and without learning disabilities and their families to complete this short survey, which should take 5-10 minutes to complete. We want to give staff the opportunity to share their views about providing care to both groups of patients and their families. We want to use the information we learn from this research to help ensure equality of access to high quality hospital care and services for all children and families in the future. The same questions are being asked for those with learning disabilities and those without learning disabilities.

All information collected will be kept strictly confidential and will be used solely for the purpose of the study. By completing the survey you are consenting to taking part in the study. Only members of the research team will have routine access to the data collected. The results will be published and presented so they can be shared with other healthcare professionals and researchers. All data that is shared will be anonymised so that participants cannot be identified.

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Thank-you

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About You

1. Are you male or female?

- Male
 Female

2. What is your current NHS band?

- 1-4
 5-6
 7
 8 and above
 Not directly employed by NHS e.g. external company

3. How many years have you worked in this Trust?

Years

4. What role do you have in the Trust? Please mark one circle

- | | |
|--|---|
| <input type="radio"/> Doctor | <input type="radio"/> Social Worker |
| <input type="radio"/> Nurse | <input type="radio"/> Psychologist |
| <input type="radio"/> Administration | <input type="radio"/> Dietetics |
| <input type="radio"/> Porter | <input type="radio"/> Pharmacist |
| <input type="radio"/> Health Care Assistant | <input type="radio"/> Psychiatrist |
| <input type="radio"/> Family Support Worker | <input type="radio"/> Family Therapist |
| <input type="radio"/> Chaplain | <input type="radio"/> Play specialist |
| <input type="radio"/> Teacher | <input type="radio"/> Speech and Language |
| <input type="radio"/> Other therapist | <input type="radio"/> Other role not listed |
| <input type="radio"/> Physiotherapist | <input type="radio"/> Domestic services |
| <input type="radio"/> Occupational Therapist | |

Part 1: Identifying and tracking CYP with learning disabilities

All the questions in Part 1 (Q.5-20) relate to children or young people with learning disabilities

Please mark one circle for each question unless instructed otherwise.

5. Has your Trust ever given you information about how to define learning disability?

Yes No Don't Know

6. How confident are you about identifying that a child or young person in your care/who you meet has a learning disability?

1 Extremely Confident	2	3	4	5 Not at all confident
<input type="radio"/>				

7. How useful do you think it is that children and young people with learning disabilities are:

	1 Extremely useful	2	3	4	5 Not at all useful	Don't know
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a) identified at an organisational level (e.g. central database, electronic patient record)?

<input type="radio"/>						
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b) visibly flagged at an organisational level (e.g. sticker on patient notes)?

<input type="radio"/>						
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8. What systems are in place in your Trust for identifying and recording that a child or young person has learning disabilities? Tick all that apply

We do not have any systems

I do not know

Documented in medical notes

Documented in nursing records

Documented electronically

Sticker on patient notes

Database

Other (please specify)

9. In your role, how easy is it for you to use these systems to identify that a child or young person has a learning disability?

1 Extremely easy 2 3 4 5 Not at all easy I do not know

10. In my role I am routinely informed that a child or young person has a learning disability

1 Strongly agree 2 3 4 5 Strongly disagree

Part 1: Meeting the needs of CYP with learning disabilities

11. For children and young people with a long term condition and learning disabilities

...

Please mark one circle for each statement

	1 Strongly agree	2	3	4	5 Strongly disagree
a) I have the necessary <u>knowledge and skills</u> to meet their needs	<input type="radio"/>				
b) I have the necessary <u>training</u> to meet their needs	<input type="radio"/>				
c) I routinely have access to the necessary <u>resources</u> to meet their needs e.g. communication aids, equipment	<input type="radio"/>				
d) I routinely have access to <u>additional specialist support</u> to meet their needs e.g. play specialist	<input type="radio"/>				
e) I routinely have access to additional <u>learning disability specialist staff</u> to meet their needs	<input type="radio"/>				
f) I feel confident to <u>communicate effectively</u> with them	<input type="radio"/>				
g) I feel confident to <u>assess and manage pain</u>	<input type="radio"/>				
h) I feel confident to <u>safely manage challenging behaviour</u>	<input type="radio"/>				
i) I work in an <u>environment that is safe</u> for meeting their needs	<input type="radio"/>				
j) <u>I am always able to deliver safe care</u>	<input type="radio"/>				
k) <u>I work in an environment that is designed to take into account their individual needs</u>	<input type="radio"/>				

12.

Please read the following statement about **Reasonable Adjustments**: The law says that all health services must think about people with disabilities. They have to ask 'What extra things do we need to do, so people with disabilities can get health services as good as other people?' These are called Reasonable Adjustments.

Please mark one circle for each statement

	1 Strongly agree	2	3	4	5 Strongly disagree
a) I feel able to identify what <u>reasonable adjustments</u> are needed for children and young people with a long term condition and learning disabilities	<input type="radio"/>				
b) I feel confident that any <u>reasonable adjustments</u> will be accommodated in a timely way	<input type="radio"/>				

Part 1: Equality of access for CYP with a long term condition and learning disabilities

Please mark one circle for each statement

13. I routinely involve children and young people with a long term condition and learning disabilities ...

	1 Strongly agree	2	3	4	5 Strongly disagree
a) when making decisions about their care and treatment	<input type="radio"/>				
b) <u>parents</u> in making decisions about their care and treatment	<input type="radio"/>				

14. In my Trust children and young people with a long term condition and learning disabilities ...

	1 Strongly agree	2	3	4	5 Strongly disagree	Don't know
a) are routinely involved in the planning of services	<input type="radio"/>					
b) <u>parents</u> are routinely involved in the planning of services	<input type="radio"/>					
c) <u>parents</u> are relied upon too much by hospital staff	<input type="radio"/>					

15.

In my Trust, children and young people with a long term condition and learning disabilities have appropriate access to:

Please mark one circle for each item

	1 Strongly agree	2	3	4	5 Strongly disagree	Not applicable
Medical care and equipment	<input type="radio"/>					
Educational provision	<input type="radio"/>					
Play and stimulation	<input type="radio"/>					
Appointments	<input type="radio"/>					
Double appointments	<input type="radio"/>					
First or last clinic appointments	<input type="radio"/>					
Flexible appointments	<input type="radio"/>					

Part 1: Overall for children and young people with learning disabilities

Please mark one circle for each statement.

16. In my Trust, I feel children and young people with a long term condition and learning disabilities ...

	1 Strongly agree	2	3	4	5 Strongly disagree
a) are always treated with <u>dignity and respect</u>	<input type="radio"/>				
b) <u>parents</u> are always treated with <u>dignity and respect</u>	<input type="radio"/>				

17. Overall I think my Trust values ...

	1 Strongly agree	2	3	4	5 Strongly disagree
a) children and young people with a long term condition and learning disabilities	<input type="radio"/>				
b) <u>parents</u> of children and young people with a long term condition and learning disabilities	<input type="radio"/>				

18. How likely would you be to recommend your Trust ...

1 Extremely likely

2

3

4

5 Not at all likely

a) to a friend or family member of a child or young person with a long term condition and learning disabilities who needed treatment?

b) as a good place to work with children and young people with a long term condition and learning disabilities?

19. What could your Trust do to support children better with a long term condition and learning disabilities?

20. What does your Trust do well to support children and young people with a long term condition and learning disabilities?

Part 2: Meeting the needs of CYP with a long term condition **without** learning disabilities

All the questions in Part 2 (Q. 21-30) relate to children and young people without learning disabilities

Please mark one circle for each statement.

21. For children and young people with a long term condition without learning disabilities

	1 Strongly agree	2	3	4	5 Strongly disagree
a) I have the necessary <u>knowledge and skills</u> to meet their needs	<input type="radio"/>				
b) I have the necessary <u>training</u> to meet their needs	<input type="radio"/>				
c) I routinely have access to the necessary <u>resources</u> to meet their needs	<input type="radio"/>				
d) I routinely have access to <u>additional specialist support</u> to specifically meet their needs e.g. play specialist	<input type="radio"/>				
e) I feel confident to <u>communicate effectively</u> with them	<input type="radio"/>				
f) I feel confident to <u>assess and manage pain</u>	<input type="radio"/>				
g) I feel confident to <u>safely manage challenging behaviour</u>	<input type="radio"/>				
h) I work in an <u>environment that is safe</u> for meeting their needs	<input type="radio"/>				
i) I am always able to <u>deliver safe care</u>	<input type="radio"/>				
j) I work in an <u>environment that is designed to take into account their individual needs</u>	<input type="radio"/>				

22.

Please read the following statement about **Reasonable Adjustments**: The law says that all health services must think about people with disabilities. They have to ask 'What extra things do we need to do, so people with disabilities can get health services as good as other people?' These are called Reasonable Adjustments.

Please mark one circle for each statement

	1 Strongly agree	2	3	4	5 Strongly disagree
a) I feel able to identify what <u>reasonable adjustments</u> are needed for children and young people with a long term condition and without learning disabilities	<input type="radio"/>				
b) I feel confident that any <u>reasonable adjustments</u> will be accommodated in a timely way	<input type="radio"/>				

Part 2: Equality of access for CYP with a long term condition and **without learning disabilities**

Please mark one circle for each statement

23. I routinely involve children and young people with a long term condition and without learning disabilities ...

	1 Strongly agree	2	3	4	5 Strongly disagree
a) in making decisions about their care and treatment	<input type="radio"/>				
b) <u>parents</u> in making decisions about their care and treatment	<input type="radio"/>				

24. In my Trust children and young people with a long term condition and without learning disabilities ...

	1 Strongly agree	2	3	4	5 Strongly disagree	Don't know
a) are routinely involved in the planning of services	<input type="radio"/>					
b) <u>parents</u> are routinely involved in the planning of services	<input type="radio"/>					
c) <u>parents</u> are relied upon too much by hospital staff	<input type="radio"/>					

25.

In my Trust, children and young people with long term condition and without learning disabilities have appropriate access to:

Please mark one circle for each item listed

	1 Strongly agree	2	3	4	5 Strongly disagree	6 Not applicable
Medical care and equipment	<input type="radio"/>					
Educational provision	<input type="radio"/>					
Play and stimulation	<input type="radio"/>					
Appointments	<input type="radio"/>					
Double appointments	<input type="radio"/>					
First or last clinic appointments	<input type="radio"/>					
Flexible appointments	<input type="radio"/>					

Part 2: Overall

26. In my Trust, I feel children and young people with a long term condition and without learning disabilities ...

	1 Strongly agree	2	3	4	5 Strongly disagree
a) are always treated with <u>dignity and respect</u>	<input type="radio"/>				
b) <u>parents</u> are always treated with <u>dignity and respect</u>	<input type="radio"/>				

27. Overall I think my Trust values ...

1 Strongly agree

2

3

4

5 Strongly disagree

a) children and young people with a long term condition and without learning disabilities

b) parents of children and young people with a long term condition and without learning disabilities

28. How likely would you be to recommend your Trust ...

1 Extremely likely

2

3

4

5 Not at all likely

a) to a friend or family member of a child or young person with a long term condition and without learning disabilities who needed treatment?

b) as a good place to work with children and young people with a long term condition and without learning disabilities

29. What could your Trust do better to support children with a long term condition and without learning disabilities?

30. What does your Trust do well to support children and young people with a long term condition and without learning disabilities?

Thank you for taking the time to complete this survey.